

# LISTENING TO STORIES OF PAIN AND JOY

Last week in the clinic, I met an 80-year-old mother, Alice, and her 42-year-old daughter, Mary. A colleague had referred them to me to have the "therapy is not working anymore" talk. Alice has end-stage throat cancer that has now metastasized. The surgeons cannot operate and the oncologists note that chemotherapy will not significantly increase Alice's life and may even worsen her quality of life.

After the usual clinical dialogue, I asked Alice and Mary why they thought they were seeing me. They really did not know. Alice wanted me to feel her hard, immobile mass in her neck, the one she said the surgeons told her they could not remove. Did I have an opinion? Could it come out some other way? Her large brown eyes looked intently at me, as if pleading for her life. My thoughts rushed through any possible answer to these questions. I heard in her voice the desperation for some hope of a fix, some way to conquer the inevitable, and some way to keep on living. I wanted so much to say that there was a new treatment, that there was a way to overcome this obstacle.

But there is no such treatment. Alice had struggled with this illness for many years, and her time had come to face the fact that she would die from it. It was my job to help her understand that and to help her figure out some way to continue living while dying. Could she find meaning and purpose in her dying days and in her suffering?



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*Physicians  
and Other  
Caregivers  
Can Help  
Patients  
Find  
Comfort and  
Meaning at  
the End  
of Life*

BY CHRISTINA M.  
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Could her hope for a cure be transformed into hope for something beyond the physical presence? How could her family find some way to deal with the impending loss of their mother?

Having walked this journey with so many patients and their families, as well as with friends and family, I had lots of shared experiences that I could draw on to provide Mary and Alice with answers and potential aids. Alice could, for example, look for hope to a specific belief in an after-life; she could spend high-quality time with her family; or, she could look at her illness as an opportunity instead of a loss.

Part of my clinical training as a physician has taught me how to provide answers and "quick fixes." It's simply a fact that, with the current economic pressures in health care, physicians and other providers are pressured to act quickly and efficiently in time-constrained office visits. The temptation, then, is to offer answers, fixes, and referrals that will move patients smoothly and quickly through the system.

But conversations with patients who are dying, suffering, or facing stress cannot be conducted in brief visits. Most of the time, they involve questions that have no answers. And attempting to provide answers to unanswerable questions can be detrimental. It can cut the patient off from further sharing and exploration of issues that are important to them.

So, instead of delineating a plan, I simply asked Alice what she thought was happening. People in such situations often have an innate sense of reality, however dressed in veils of hope. Mary, clearly nervous and hopeful, filled in some relevant historical information. Alice added in the details of her illness. The conversation stayed focused on the medical.

At one point, I asked about her husband and other family members. Her husband had died three months before of a chronic illness. I



expressed my condolences. Mary was clearly struggling. I gently touched her knee, and tears started streaming down her face.

Alice just looked at her with such compassion and warmth, but perhaps a sense of wanting to spare her yet another parent's death. My own eyes filled with tears as I empathized with them. Again, my mind raced to hope that maybe her medical team could come up with a treatment to delay the obvious. Perhaps God or fate would be merciful and allow her more time so that both Alice and her family could heal from one loss before facing another.

The medical talk then turned into a profound conversation about Alice's illness, her dying, and how she and Mary would deal with that. Part of my role, was to be direct in a compassionate way, about Alice's prognosis. It is important not to avoid the "D" word, death. My stating that she will likely die from the illness and that curative therapy is no longer an option was critical in turning the conversation from one about medicine to one about her dying.

I asked them what had helped them deal with the death of the man who had been the husband of one and the father of the other. Alice said her faith and her religious background as a Catholic helped her. Her relationship with God was central to her life, she told me. She trusts in God and is comforted by the thought of a life after death with Him and her husband. As a result of her extensive head and neck surgery, she was self-conscious about her scars and did not attend church much. Interestingly, I did not even notice her scars because her character and love show through her eyes.

Mary is very spiritual and religious and finds both the belief and the church community very important to her. She finds meaning in taking her mother to church, when her mother is up to it. Mary clearly was a partner in her mother's life. Alice finds meaning in her relationship with God, but also as a mother and caregiver. The pain that Alice believes her daughter will feel in her dying is something I sensed Alice was afraid of, even though she was not ready to talk about that in this initial visit.

There were, in this conversation, many moments of silence and shared tears. These moments were interspersed with laughter and "negotiation"—laughter to ease the heaviness of the occasion, and negotiation and bargaining to see if a different outcome might possibly be arranged. The conversation flowed from listening to informing to planning. It was not static and certainly could not be written into a "how to have these talks" format applicable

to all such patients. Because each person is an individual, the way these conversations flow varies from person to person. The common thread is listening, caring, and loving.

### SPIRITUALITY

Spirituality is central to the care of all patients and especially those dealing with suffering, loss, and dying. Spirituality can be seen as that part of all human beings that seeks meaning and purpose in life. For many people, meaning can be found in religion, but it can also be found in relationship with a transcendent being or concept outside of a formal religion, or in work, family, or other relationships. People can find meaning in values or philosophical beliefs, such as doing good for others or making a difference in the world. Some people talk of their spirituality as that sense of peace or wonder that they experience in nature or art or music. The ways people find meaning often change over their lifetimes.

What gives meaning to someone when he or she is 20 years old and healthy may be very different when that person faces a serious illness or simply ages. Illness and loss may cause people to ask existential questions about who they are or what gives value to their lives. These experiences can be life changing, in that they offer people an opportunity to search for meaning in a way that they might not have chosen were it not for the illness or loss. In that sense, the illness may be seen by some as positive and life enhancing, even in the face of dying. As a clinician, I hope to offer patients opportunities and resources for their search for meaning and purpose, if that is something they are interested in exploring. A health care system that focuses only on the physical does not afford patients and their families the time, resources, and attention to focus on this important aspect of their care.

But spirituality is also relational. The patient's spirituality and that of the clinician are both part of the healing equation. This is where spirituality becomes so important to the care of patients. The physician or other health care professional forms a caring partnership with the patient and family. Out of that partnership arises the opportunity for healing.

People often come to the health care system with profound experiences of suffering. They are broken and feel as if their lives have become fragmented. Healing is the restoration of wholeness. But it cannot occur in a vacuum. Healing requires partnership. The fragmentation can make people feel isolated and lonely in the midst of tremendous spiritual pain. The love and care of

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others can support the person as he or she mends the brokenness. Patients may do better if the relationship with their physician and health care professionals is one of a partnership. Partnership implies that the journey is one of shared experience where two people work together toward a resolution rather than one in which the expert doles out advice, leaving the patient to sort through the problems alone.

### THE SPIRITUALITY OF THE CAREGIVER

Professional caregivers also have meaning and purpose in their own personal and professional lives. What gives meaning to the clinician may be integral to why that person is a physician or other type of health care professional. Many colleagues speak of being "burned out." They have lost a sense of meaning in their work and hence their passion and sense of mission. Nurturing whatever gives meaning to one's profession and encouraging it to grow—this may be one way to overcome burnout and continue to be effective, caring, and compassionate healers. Furthermore, as we caregivers explore our own sense of purpose and what gives us meaning in our lives—our spirituality—we become better able to understand and relate to our patients.

Many residents and medical students have asked me if it is permissible to show our emotions with our patients. They wonder whether they should maintain distance and stay uninvolved in order to be more effective and less stressed. My response is that when a physician works so hard to stay distant and unattached, both the patient and the physician suffer. The physician cannot expect to treat people who suffer and die and be untouched by those experiences. Denying one's emotions eventually takes its toll. Colleagues who have done that tell me that they wake up one day and realize that their lives have lost meaning. Some talk of the stored-up tears that come flooding out when a personal loss unveils the years of hidden and unacknowledged grief.

Patients sense the detachment as distance and lack of caring. Many surveys indicate that patients want to have compassionate and humane physicians. This is critical to building trusting relationships. Without trust, patients are unlikely to share the issues that are important to them, including many medical issues. In such cases, the delivery of care will not be as good because physicians will lack the whole picture concerning whatever is going on with the patient. Patient-centered care requires that physicians and other care providers create an atmosphere in which patients feel that they can raise any issue that is of concern to

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them—physical, emotional, social, or spiritual. The American College of Physicians has noted that it is the obligation of physicians to attend to all dimensions of a patient's suffering, the spiritual and existential as well as the physical. In order to do this, the physician needs to know how to address those concerns. This is integral to patient-centered care.

### ADDRESSING PATIENTS' SPIRITUAL ISSUES

The first requirement in addressing patients' spiritual concerns and the delivery of spiritual care is *presence*. Physicians and other professional caregivers need to be fully attentive to patients and fully present during their encounters with them. Essential to this is compassion and expression of genuine concern and care. Intellectual attention is not enough. For partnership, love and compassion are essential. Out of this foundation flow the ability to listen to the patient, and all of his or her concerns, and the ability to connect to and empathize with him or her.

This is the root of spiritual care. Beyond this, one needs to know how to elicit information about the patient's spiritual beliefs and what gives them meaning. Some physicians and health care professionals listen for clues about spiritual beliefs and then follow the patient's lead. I think it is important to have a general question that invites a conversation about spiritual beliefs, if that is what the patient wishes to do.

A patient may think that a physician in the traditional clinical setting will not be interested in his or her spiritual beliefs. To help patients in such situations, the physician (or other health care professional) might begin by asking an open-ended question, such as, "Do you have spiritual beliefs that help you cope with difficult situations?" The caregiver can then listen to the response, trying to discern how important these beliefs are to the patient, whether they give meaning to his or her life, and how they influence his or her health care decisions, and also whether the patient belongs to a community (religious or secular) of people that might lend him or her needed spiritual support.

Finally, the physician or other caregiver can think about what actions to take with the information the patient shared. If there are signs of spiritual distress or conflict, referral to a trained spiritual care provider, such as a chaplain, spiritual director, or pastoral counselor, may be indicated. Some patients may benefit from meditation or yoga. Others may describe spiritual practices that might be integrated into the therapeutic

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plan. In all of these conversations, it is important to be respectful of the patient and noncoercive. And it is critical to realize that spiritual care is interdisciplinary care. All members of the health care team should address patients' spiritual needs and form caring relationships with them. The physician, in considering the action needed, should remember that other members of the team, particularly chaplains or the patients' own clergy, are partners in the spiritual care.

Some of my colleagues address spiritual concerns by asking the patient what gives him or her meaning. From my own clinical experience, I have found that this question is, in the clinical setting, sometimes seen as esoteric and confusing: What does meaning have to do with illness? Instead, I usually wait to ask that question until *after* I've asked the open-ended question about spiritual beliefs. The patient's response to the spiritual belief question then often leads in naturally to the question about meaning and purpose in the patient's life.

Just as with the "D" word—dying—it is, I think, unwise to be afraid to talk openly about spirituality and religion. Spirituality is integral to who we all are as human beings. It is very relevant to the health care setting, because it is the way people understand who they are and is a lens through which people understand the world. It is a way people may cope with suffering, and also a way people come to understand what their illness and their dying mean.

### COMPANIONS ON THE JOURNEY

Alice and Mary will be returning to my office next week. I have held them in

my heart for the past two weeks and have thought of them often. We ended the last visit with a plan to think about what had been said, and a recommendation that Alice think about a "dream list" of things she may want to do in whatever time she has left. Mary wants to pray more about the situation; Alice wants to think and come to terms with her choices.

Next week, I will listen to their stories, what they are thinking about, what they are afraid of, and what they wish and hope for. Together we will walk a journey that is uncharted and uncertain. Along the way, I will learn more about their lives and what gives meaning and hope to them. I will work with the hospice team—nurse, chaplain, and social worker—to help meet the needs of this family.

There will be tears and laughter. There will be sadness and happiness. Maybe Alice will find a deeper, new sense of meaning in her life. Maybe she will say, as many of my patients do, that life is richer and fuller than ever before. Maybe she will have deep despair that does not result in resolution. Maybe her desire to be present to her daughter will give her the will to live as long as she can, for her daughter.

These are the unknowns, but the journey is Alice's and I am simply her companion. I will support her and her daughter through the process and offer her any resources that might help her. I hope for peace and meaning in Alice's and Mary's lives. And when Alice dies, I will grieve her loss. She will become part of my life forever, as have all the patients I have been so privileged to care for, to partner with, and to love. □

## THE ETHICS OF LOVING CARE

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